

Proclamation 5581 of December 2, 1986

### National Epidermolysis Bullosa Awareness Week, 1986

*By the President of the United States of America*

*A Proclamation*

Epidermolysis bullosa is a group of hereditary, blistering disorders that involves the skin and mucous membranes, especially mucous membranes of the mouth, eye, and gastrointestinal tract. Symptoms of the disease can resemble severe burns and can be very painful and debilitating. The disease can lead to scarring, malnutrition, anemia, and even premature death.

As many as 50,000 Americans, most of them children, are affected by epidermolysis bullosa. The disease not only disables people physically and emotionally, it also places a severe financial burden on their families.

Basic research is just beginning to reveal the underlying causes of epidermolysis bullosa. Recent developments in biology, biochemistry, pathology, immunology, and genetics are all being employed to study the disease. The main objectives are to understand the basic mechanisms that lead to this distressing disorder and to develop therapies directed at correcting these effects.

The Federal government and private volunteer organizations have developed a strong and enduring partnership committed to research on epidermolysis bullosa. I am confident that this concerted effort will ultimately uncover the cause and cure for this devastating disease.

The Congress, by Public Law 99-459, has designated the week beginning December 1 through December 7, 1986, as "National Epidermolysis Bullosa Awareness Week" and authorized and requested the President to issue a proclamation in observance of this event.

NOW, THEREFORE, I, RONALD REAGAN, President of the United States of America, do hereby proclaim the week beginning December 1 through December 7, 1986, as National Epidermolysis Bullosa Awareness Week. I call upon all Americans to participate in activities designed to heighten awareness of the plight of epidermolysis bullosa sufferers.

IN WITNESS WHEREOF, I have hereunto set my hand this second day of December, in the year of our Lord nineteen hundred and eighty-six, and of the Independence of the United States of America the two hundred and eleventh.

RONALD REAGAN